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AUTHOR Schock, Nancy C.
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ABSTRACT

Practical information on children with muscular dystrophy is intended to help parents and teachers facilitate their inclusion in mainstreamed classrooms. Major topics addressed include the following: transportation arrangements; providing full information to the teacher regarding the child's specific abilities and physical limitations; accessibility within the physical school environment; adaptive equipment, lifting, and managing a wheelchair; the role of the teacher in promoting social adjustment and positive peer relationships; individualized physical education; tutoring services during extended school absences; and career guidance. Names and addresses of organizational resources and publications are included. (JW)

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The Child with Muscular Dystrophy in School

Nancy Schock

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The Child with Muscular Dystrophy in School

Written by Nancy Schock, mother of five children,
one of whom has Duchenne muscular dystrophy.

Originally published by the Massachusetts Teacher's Association, 1976.

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Reprinted by the Appalachian Satellite Program Resource Center,
Keyser, W. Va., 1977, 1978, 1979.

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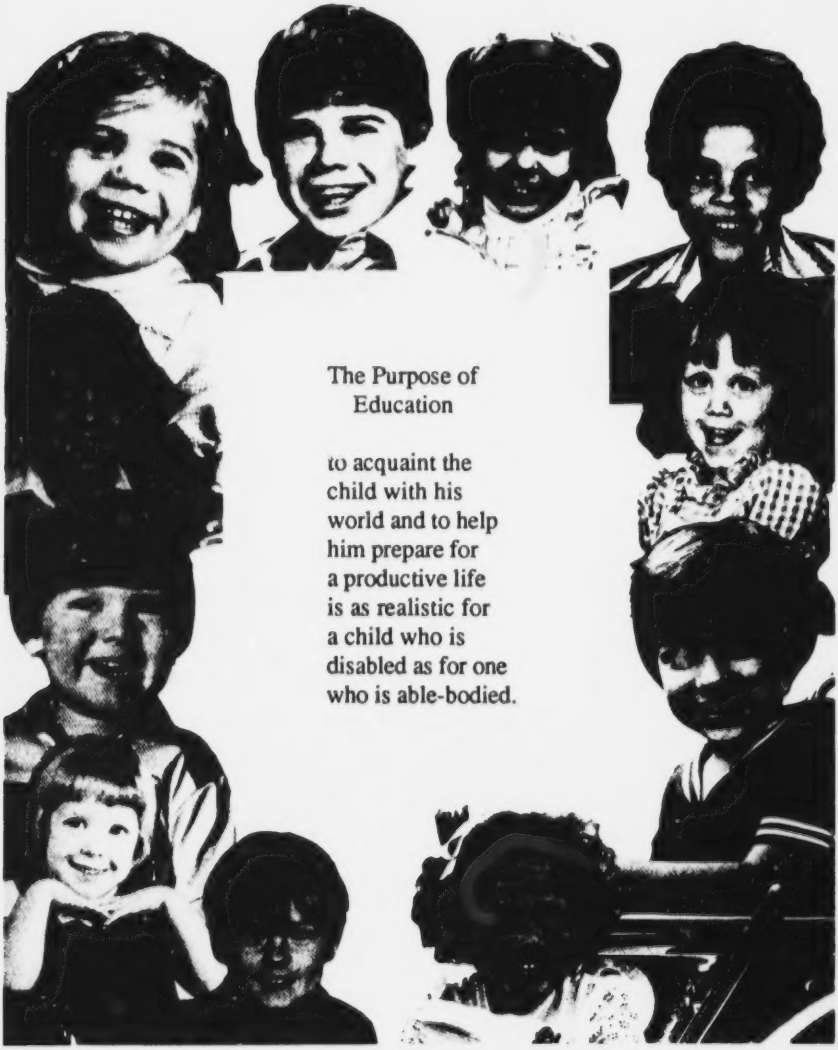

The Purpose of Education

to acquaint the child with his world and to help him prepare for a productive life is as realistic for a child who is disabled as for one who is able-bodied.

By enacting Chapter 766 on September 1, 1974, the Commonwealth of Massachusetts mandated that all children including those with physical disabilities be provided a public school supported education designed to meet the students' particular needs.

One year later on November 29, 1975, the Federal Government guaranteed by passage of PL 94-142 the right of children all over the United States to obtain a free and appropriate education in the main stream of educational life.

The author's goal in writing this booklet is to aid the integration of these children by providing information to parents and teachers.

Muscular dystrophy does not directly affect the child's ability to learn. However, the resulting confinement, narrowness of opportunity to experience life, and limited interaction with other people can diminish personal as well as intellectual growth. It is apparent that inclusion in the public schools can greatly enhance the development of these children.

The following description of muscular dystrophy, presented for your information is taken from **Patient and Community Services**, a publication of the Muscular Dystrophy Association.

> "Muscular Dystrophy is the general designation for a group of chronic diseases whose most prominent characteristic is the progressive degeneration of the skeletal or voluntary musculature. They are for the most part hereditary conditions although spontaneous occurrence as the result of genetic mutation, is not uncommon. The genetic pattern and therefore, the mechanism by which the desease is transmitted - varies in the different types of dystrophy. There are also variations in the age of onset, in the muscle groups first affected, and in the rate of progression. As a rule, it can be said that the earlier clinical symptoms appear, the more rapid is the progression."

The progressive nature of the disease requires that the person who has muscular dystrophy and whoever else is involved in his life continuously adjust to his new physical limitations. The range of life expectancy varies from death in infancy in the most severe cases to normal span in the most mild.

The Muscular Dystrophy Association provides many services for people with muscular dystrophy and related diseases; including assistance in selection, purchase and repair of orthopedic appliances, free clinical diagnosis and follow-up care, transportation for some purposes, summer camp and recreational activities. For services not included in MDA'S program, the Association acts as liaison between the person needing help and the appropriate agency.

MDA publications are available free of charge. Some are listed below.

Annual Report
Clinics - New Dimensions in Patient Care
Medical Services for the Patient, the family, and the Community (English & Spanish)
A Special Place (MDA Camps)
Everybody's Different - Nobody's Perfect
101 Questions about Muscular Dystrophy
Fact sheets on specific disabilities

For information or assistance, the reader can look in the telephone book for the nearest office or write to the Muscular Dystrophy Association, 810 Seventh Avenue, New York, N.Y. 10019.

TRANSPORTATION TO SCHOOL

The first great hurdle for a physically handicapped child is getting from home to school.

School systems are responsible, by law, for special transportation of children unable to walk or ride the regular school bus. Sometimes, adapted vans are used, or special buses, public taxis or private cars. (1) It is hoped that the method of transportation available will provide a comfortable, anxiety free trip, presenting the child in the right place at the right time.

As he prepares to be transported, some of the same questions trouble the student and his parents. Is the driver responsible, careful and knowledgable regarding lifting the child? (2) Will they arrive at school on time and at the right door? Will someone be there to open the door? (Special concern in cold or bad weather.) Can the child handle necessary books and personal belongings? Will anyone speak to him?

These real and ever-present anxieties are no doubt mixed with a varying amount of joy and excitement in anticipation of the school day ahead.

1 Special lifts or ramps can be built into vehicles for boarding wheelchairs. Such vehicles need floor clamps or some other restraint to keep wheelchairs from moving while travelling. This equipment is available from medical supply companies listed under Hospital Equipment and Supplies in the Yellow Pages of the telephone directory.

2 Instructions on lifting, page 16

IN THE CLASSROOM

Once the child has entered the classroom, his well-being, especially in the beginning, depends largely on the teacher; and in order to act wisely on the child's behalf, the teacher must be well informed regarding his specific abilities and physical limitaitons.

There are many forms of dystrophy and, as each person is at a different stage, stating generally what to expect at a certain time is impossible. The **student, parent, therapist,** or **doctor** can probably supply answers to specific questions concerning current physical ability. The **school nurse** can be supportive in this and other efforts. In fact, in some school systems the school nurse acts as advocate for the child who has a physical disability.

Some pertinent questions follow :

Can the child walk? Does he fall easily? If so, what precautions should be taken? Can he walk upstairs if necessary?

If in a wheelchair, is he comfortable? Would he like to be shifted in the chair occasionally? Who can move him? How should this be done? Can he handle his papers, books, pencils? Can he work at the desk? Write? How will he move from one location to another?

Does he need help using the toilet? What kind of help and who should provide it? Can he get to the lunch room? Handle his money? Feed himself? Use the telephone if necessary? What arrangement has been made for his evacuation in case of fire? Is the child who is disabled aware of this? Are his classmates?

A young person with dystrophy who spent 13 years in public school contributed to the previous list of questions and in conclusion added, "The teacher and classmates should **KNOW** the nature of the disability and that there are occasions when the person needs help."

After examining problem areas, it becomes apparent that most needs fall into two categories - those that can be satisfied by people, and those that can be minimized by modification of the environment - including buildings, facilities, and outdoor space and equipment.

ACCESSIBILITY

Architectural standards for providing accessibility are established, and specifications are available from many sources.

Generally speaking, a person using a wheelchair for mobility needs enough space in which to maneuver, a ramp or lift whenever there is a change in grade (curb, step), and some consideration regarding the surface of the path of travel. This includes parking areas, approach and entrance to buildings, and all areas that the student will be transversing within and outside the building.

A mobility impaired person who is still ambulatory may also need ramps and lifts and a safe surface on which to walk. In addition, he may need railings, handles, and grab bars for support, and doors that are easy to open.

It is important to arrange space in the classroom, auditorium, lunch room, etc. so that the wheelchair user can mingle with the other students. This is a much more desirable arrangement than providing space in the back of the room or in the aisles.

New or renovated public buildings and buildings used by the public must comply with standards for accessibility, and the responsibility of the Architectural Barriers Board is to enforce these regulations. In order to obtain specifications for educational buildings, or any other information regarding barrier-free design, call your state Architectural Barriers Board or contact the National Architectural Barriers Compliance Board.

330 C Street, 8W
Room 1010. Sewitzer Building
Washington, D.C. 20202

Accessible buildings, restrooms, parking areas or public places that meet the necessary standards may display the symbol of access.

Publications

Kliment, Stephen A. *Into the Mainstream, a Syllabus for a Barrier Free Environment*, prepared under a grant to the American Institute of Architects by the Rehabilitation Services Administration of the Department of Health, Education and Welfare, 1975.

American Society of Landscape Architects, Office of Policy Development and Research (HUD), *Barrier Free Site Design*, U.S. Government Printing Office, Washington D.C. 20402, 1975.

National Center for a Barrier Free Environment, *Report*, bi-monthly publication, Suite 700, 1015 Fifteenth St., N.W., Washington, D.C. 20005.

EQUIPMENT

Although there is equipment, modified to make life easier for people who are disabled, many in need are unaware that such equipment exists. For example: there are wheelchair bags and attachments for carrying books and supplies, writing surfaces for use as desks, arm supports to increase reach and scope, foot rests, seat inserts, etc., for comfort - and more. The advantage of adding extra conveniences has to be weighed against the awkwardness in handling them. In some instances, it may be easier for a classmate to help than for the child to add a cumbersome object to the possessions which he may already have difficulty managing.

For advice, refer to an **Occupational Therapist**, an expert in this field. Or, refer to the office of the Muscular Dystrophy Association. Its personnel will help suggest equipment, or provide direction to the appropriate source of assistance.

A person unable to hold a book or turn pages is eligible for the free library service administered by the Library of Congress, Division for the Blind and Physically Handicapped. Following application, the student will receive a special phonograph and/or cassette player and soon after, an information sheet, catalog, and library instructions on how to obtain books and magazines. Literature includes thousands of selections both fiction and non-

fiction, classics, current best sellers and popular magazines - all on records or tapes. For additional information on "Talking Books," inquire of the Muscular Dystrophy Association or write to the:

National Library Service for the Blind and
Physically Handicapped
Library of Congress
Washington, D.C. 20542

Another resource is ALBEDATA, a computerized information database with listings of equipment and assistive devices. For specific details, contact Marion G. Hall, ABLEDATA System Manager, National Rehabilitation Information Center (NARIC), 4407 Eighth St., N.E. Washington, D.C. 20017, (202) 635-6090

HUMAN RELATIONS

When problems are worked out for the physical survival of the child who is disabled, the great and compelling need is for social integration. Attitude of the other children toward their disabled classmate is probably the greatest single factor which will determine the quality of his school life. Again, the teacher's role is critical. She/he can help the class understand that the child with dystrophy is "whole" except for his inadequate muscles. He has special talents and interests and the same spectrum of desires as other children. He wants to have friends, to move freely, to play, laugh, explore, and to succeed.

The teacher should, as much as possible, treat the child in the same manner as his classmates, expect the same effort in academic work, and include him in all activities.

Living with the inconvenient body is the child's condition of being. If his promise is to be fulfilled, he needs positive support in developing attitudes, help in finding solutions, and respect for effort and achievement. (This is probably true for all children.) Pity is destructive; continuous reference to the disability is tiresome. When teachers, classmates, and others can look past the disability and see the person, integration is a reality.

Physical Education is one area which needs special consideration - for the child who has muscular dystrophy and for the teacher. As the only way to slow contractures and the accompanying disability is by much movement, exercise and stretching, part of the physical education activity planned for him (her) could well be a supervised therapeutic program including prescribed exercises and physical therapy. This will probably be increasingly important as he becomes older.

Regardless of the disability, a child will want to be and should be included in some class activities; especially those that are social and recreational in nature. Taking part in a game or sport is fun and any child should have a chance to play. By modifying rules, area of play, method of locomotion and type and size of equipment, participation is possible in almost any activity.

The manipulation of rules, etc., is to allow the child who is disabled to be included and not to attempt a cover-up of his physical condition. There is no reason why he should feel inferior because his body does not perform as well as that of someone else. He is not responsible for its impairment, just has to learn to make it work as well as possible for him.

Swimming is an activity which is particularly beneficial. Being suspended in water frees the child from some of his physical limitations and allows him to move more easily. Highly motivated teachers have been able to help children who are severely disabled develop individual swimming techniques by using the strength and skill available to them.

Pleasure accompanying physical achievement should be experienced while the child's body has some ability to perform. Self-image, so fragile in a child with dystrophy, can be improved by achievement in realistic physical goals.

Additional information on adapted physical education is available from the *American Alliance for Health, Physical Education, Recreation, and Dance, Unit on Programs for the Handicapped*, 1900 Assocation Drive, Reston, VA 22091. (202) 476-3400.

ARTS (By John Hagerty, Arts Specialist)

"The arts, a basic form of human communication, can offer varied experiences to interest, to motivate, and to engage all students. Music, painting, drawing, photography, film, and television provide young people with a range of learning experiences which fit their individual needs. Children can achieve intellectual, emotional, aesthetic, physical and spiritual growth through the arts. Since arts activities are so varied, and the types of growth which result are so diverse, emotionally and physically handicapped children often excel when they work in an art medium which fits their personal capabilities."

A useful resource is the *National Endowment for the Arts, Office for Special Constituencies*, Washington, D.C. 20506. (202) 682-5531.

HOUSEHOLD ARTS

Inclusion in household arts classes can give the student who is disabled an idea of the organization, labor, skills, customs, and economics of creating a home. And, the experience can motivate him to figure out how to use his talents in sharing the work.

INDUSTRIAL ARTS

Similarly, participation in industrial arts can teach the student how some manual work is accomplished. If he/she cannot take part fully in fashioning the object, he can participate in its planning, see how it is made, and appreciate its completion.

SUBSTITUTE TEACHER

In anticipation of being absent, the classroom teacher should plan ahead so that the **substitute teacher** or someone else designated will be prepared to provide for the special daily needs of the child.

ABSENCE FROM SCHOOL

If a child, for health reasons, is absent from school frequently or for extended periods of time, he/she is eligible by law for a home/hospital tutoring program. (Provision of PL 94-142).

Parents may have to accept the responsibility for initiating this part of their child's educational program. Its success will probably depend upon the combined efforts of the people involved - tutors, regular classroom teacher, parents and hospital staff, and their ability to coordinate the medical, educational, and daily living activities.

Every state has a Department of Education, and Division of Special Education, and every school system includes a person or persons responsible for seeing that the special needs of a disabled child are satisfied. The special educator or concerned teacher can refer to the Division of Special Education for assistance.

The *National Information Center for Handicapped Children and Youth* (P.O. Box 1492, Washington D.C. 10013) supported by the U.S. Department of Education provides:

Publications about specific disabilities or areas of interest.

Addresses of parent organizations - local, state, and national.

Information about other resources.

Ideas on how to work with schools and other agencies.

The Federation for Children with Special Needs (312 Stuart St., Boston, MA 02116 (617) 482-2915) is a parent run information and training center coordinating a national network of parent centers. People seeking information about the Federation's program of services, or that of any of the other centers can write to the above address.

GUIDANCE

It is often assumed that anyone who is disabled be prepared for a trade. In reality, the progressive nature of muscular dystrophy makes it necessary for the person so limited to depend upon the ability of his mind to function well and not on his body which performs with increasing difficulty.

Careers in law, medicine, architecture, the ministry, many areas of education, art, music, and writing are possible. People with muscular dystrophy have been successful in each of these fields. Others have been employed as guidance or rehabilitation counsellors, editors, police dispatchers, receptionists, bank clerks, book reviewers, and radio broadcasters. This is by no means a complete list, but is varied enough to provide some ideas for vocational goals.

As self-employment has been the solution of financial independence for many disabled people, inclusion of business principles and procedures in the course of study would be beneficial. The following quotation emphasizes the point:

> "It has been recognized by professionals in vocational rehabilitation that, for severely hadicapped clients, self-employment is not only an alternative to placement with an employer, but may be the most desirable form of placement". Tseng, M.S., EdD, and Parker, Lionel E. "Self Employment for the Severely Handicapped." Rehabilitation Literature, May, 1976, p.140.

Whatever activity relating to survival or occupation that the person who is disabled pursues, it is apparent that he needs to be able to communicate well. Therefore, adequate attention must be given to developing language skills, And, because there is equipment to provide some independence for the person whose physical ability is decreasing, an understanding of electronics and mechanics will be useful. He may not be able to repair his equipment, but will have greater success in having it repaired if he understands how it works.

Education beyond high school is desirable and possible. Although surviving at a college or university may not be easy, an increasing number of young people who are disabled are managing to do so. In the past 5-10 years, many post-secondary institutions have become physically and programatically accessible to students with mobility and other impairment; and, in addition, have special centers for support and sociability.

In order to see for himself whether or not he can function at the college of his choice, the perspective student may wish to visit before enrolling.

High school *guidance counselors*, and *college admissions personnel* will assist students in acquiring information about programs at specific post-secondary schools.

The State Division of Vocational Rehabilitation also provides career assistance and services for people who are disabled. If unable to locate the nearest office by looking in the phone book, the student can call the information center at the State House and inquire.

The Association on Handicapped Student Service Programs in Post-Secondary Education was organized in 1978 to strengthen the professionalism, expertise, and competence of personnel working with post-secondary handicapped students. Inquiries can be directed to AHSSPPE, P.O. Box 21192, Columbus, Ohio 43321, (614) 488-4972.

ADDITIONAL CONCERNS, IDEAS, COMMENTS

HELP IN THE BATHROOM

Although the student with dystrophy will try to arrange his personal habits so that his needs are minimal, occasions will arise when help is essential. It should be available. Asking for and accepting help is difficult; if the child could assist himself, he would.

LIFTING (by David O'Toole, MD. Former Director of MDA Clinic.)

> "In searching for the safest and most comfortable method of transferring a child with muscular dystrophy, there is very little written. Experience has taught us one very important thing, however. When it comes to assisting in position changes of the child in his wheelchair, transferring from chair to mat or bed and back again, there is no textbook that can demonstrate the proper method for each individual like his mother or father. Each child is different; each has certain fears about being moved, each has favorite positions, and all children have fears of being dropped. Therefore, in our clinic we ask the mother to demonstrate the way she transfers her child. A brief five minute course by parents to bus drivers, teachers, teaching aides, and so forth will increase safety and comfort, and will definitely instill confidence within the child and in the person entrusted with the transfers.
>
> As for pushing the wheelchair, it must be remembered that the person pushing must be competent and have good judgement. Speed should be a comfortable walking speed, so that the operator has complete control. To advance over thresholds, the chair is tilted back gently so that the front wheels clear the obstruction. If these simple common sense rules are observed, there should be no problems with the wheelchair."

MANAGING BOOKS AND OTHER MATERIALS

Often hands work with difficulty and books or pencils slip to the floor. It is a simple matter for a classmate to retrieve any such item if he is aware of the need. Lack of understanding or concern can create an unnecessary hardship for the disabled child.

CLASSMATES

Classmates and others may be concerned that association with the student will affect them adversely. Muscular dystrophy is not contagious and that fact should be general knowledge.

PARENTS

Having had experience in creating solutions for their disabled children, parents are a valuable resource for teachers; and as the disease progresses, they can share in finding new answers to new problems. However, coping with such a severe disability has probably taken an emotional and physical toll. The school and community will do well to use any resources available in order to provide support for the family.

ADDITIONAL REFERENCES AND RESOURCES

ACCESSIBILITY

American National Standard Institute (ANSI)
1430 Broadway
New York, NY 10018
Publication: *Minimal Federal Guidelines - Requirements for Accessible Design.*

Office of Technical Services
or
Office of Compliance and Enforcement
U.S. Architectural and Transportation Barriers Board
330 C. Street S.W. Room 1010
Washington, D.C. 20201

Naitonal Center for Barrier Free Design
Suite 700
1015 Fifteenth Street N.W.
Washington D.C. 20005
(202) 466-6896
Publicaiton: **Report**, technical information of accessibility.

EDUCATION

Association for Care of Childrens' Health
3615 Wisconsin Ave., N.W.
Wahington, D.C. 20016
(202) 244-1801
Excellent Resource; guide for teachers, children in hospitals.

The Association for Severely Handicapped
7010 Roosevelt Way, N.E.
Seattle, Washington 98115
(206) 523-8446
TASH stresses the importance of integration in living, working, and learning; maintains a register of professional contact people available for assistance with specific eduation problem.

PUBLICATIONS

Accent on Living
P.O. Box 700, Gillim & High Road
Bloomington, IL 61701.
Quarterly, $5.00 year.
Accent on Living, Inc., is a non-profit organization serving disabled persons by collecting and disseminating specialized information. Services are available through *Accent on Living*, a quarterly magazine; *Accent on Information* , a computerized retrieval system; and *Accent Special Publications*.

The Exceptional Parent
605 Commonwealth Avenue
Boston, MA 02215
Bi-Monthly $16.00, individual $24.00 organization.
Practical guidance for everyone concerned about children with disabilities, professionals as well as parents.

Programs for the Handicapped
Clearinghouse on the Handicapped Office of Information and Resources for the Handicapped.
Room 3119, Switzer Bldg.
Washington, D.C. 20202
Free. Includes information on federal on programs, current issues, and publications.

Rehabilitation Gazette
4502 Mayland Avenue
St. Louis, Missouri 63108
Yearly: $10.00
Publicaiton by volunteer staff whose aim is to reach, to inform, and to dignify the disabled throughout the world.

The Source Book for the Disabled
Glorya Hale
Paddington Press Limited, New York and London, 1979.
An illustrated guide to easier and more independent living for physically disabled people, their families, and friends.

CONCLUSION

Successful integration in the public school can allow the child who is disabled to have as full a life as possible during the growing years, can provide classmates and others the opportunity to share his special human qualities, and can prepare the student to accept at least some of the responsibility for his own well-being. He will probably always need physical assistance, but with adequate education and encouragement, can learn to make the decisions necessary for determining the direction of his own life.

This booklet is a beginning. Although written primarily for mainstreaming children with muscular dystrophy in the public schools, it includes material useful for teachers of other children. If you, the reader, have concern for some area of school life untouched or inadequately presented; or if you have any comments to add please write: Nancy C. Schock, 8 Marrett Road, Lexington, Massachusetts, 02173.